ADVOCACY

AzMyelomaNetwork@cox.net www.ArizonaMyelomaNetwork.org

Glendale. AZ 85308 Tel. 623,388.6837

The Newsletter for People Interested in Multiple Myeloma

Vol. 1, **No.** 5 **Jul/Aug 2006**

Dear Friends of AzMN:

I know that everyone is busy, taking some vacation time, spending time with family, and trying to stay cool. I know that none of us need more work or more demands on our precious time, but we need your help to raise awareness about myeloma and to raise the funds that will help us achieve our goals. Some of you are already helping us to find 'golfers,' sponsors, and raffle/auction gifts for our **October** 5th Charity Golf Event (please see our Golf Flyer on page 2) and we really appreciate it. Every little bit helps, whether it is a donation of \$5 or a certificate for dinner or lunch at a local restaurant, movie tickets, a gift basket from AJ's or one you make yourself. Nothing you give is too small because we will put it together with some other gifts.

Remember, you don't have to play golf to know someone who does play, and if it is only one person, we'll find a 3-some for him or her. If you would like to sponsor a 4-some such as our Mayo doctors and researchers who do so much for us, then let us know. Or, if you, or someone you know, wish to be our 'Program' or printing sponsor, that would be great; or our box lunch sponsor. If not money, we would be glad to barter for a service or product. In return, sponsors and donors will receive recognition in our Golf Event Program, on our website.

Just call Lyman at (480) 296-4486 or me at (623) 388-6837 and we will gladly help out or follow-up on any leads. We also want to remind all of you who are not golfers, that you and your spouse, partner, and/or friends, can attend our dinner at **The Raven Golf Club at Verrado**, at 5:30 pm and enjoy a lovely Arizona Cookout dinner, DJ music, raffle and auction at the lovely clubhouse, all for \$35 per guest.

Fondly, Barbara

Peripheral Neuropathy

by: Jack Kavanagh

Peripheral neuropathy is a term used to describe disorders resulting from injury to the peripheral nerves. Peripheral nerves are those that connect the Central Nervous System to the muscles, skin and internal organs. There can be many causes for the illness, and they include: immune system problems; nerve tumors; drugs; infections; kidney disease; poor diet; alcohol abuse and nerve compression (carpal tunnel syndrome).

Many Multiple Myeloma (MM) patients are affected by peripheral neuropathy. It is a side effect of some drugs used to fight MM. For instance, it is estimated that up to one third of patients taking Thalidomide will experience peripheral neuropathy. Sensations include numbness, tingling and pain in the feet or hands, weakness in the arms or legs, unsteadiness while walking, and the feeling that you are wearing gloves and stockings when you are not.

Treatment depends on the cause. For MM patients with thalidomide induced neuropathy, this can mean: a reduction in the dosage of thalidomide; a change of treatment; spaced dosages; pain medicines; anodyne therapy; surgery; vitamin and mineral "cocktails," supplement orcombination ofthese possible remedies. Unfortunately for patient, none of these is a "cure," but they may relieve distress. For those patients having success with thalidomide but who suffer from neuropathy, their dilemma may be whether to continue on the drug and endure neuropathy rather than moving to a more dramatic treatment.

One of the striking things about neuropathy is how little research is being done. It is a disease that has an estimated 20 million sufferers in the United States, large numbers of whom are diabetics. It is estimated that 10% of diabetics are afflicted. The disease occurs in numerous forms, and this may be part of the reason it is somewhat neglected in the research arena. It is referred to as "The most common disease you never heard of."

The Neuropathy Association is one of the principal patient advocates. Their membership fee is a very modest \$35 and they publish a newsletter. They are based in New York City and for further information; you can contact them at 212-692-0662, www.neuropathy.org or by E-mail at info@neuropathy.org.

The Healing Power of Humor by: Maria Patti

It was always told that laughter is the best medicine. Research has shown many patients suffering from diseases and depression do much better by getting involved in some type of comedy relief. It is often found that people have a "healing power" when watching even some reruns of The Three Stooges or see a stand-up comedy show.

Maria Patti has proven this by going to senior centers and visiting Parkinson's Disease centers doing workshops entitled, "The Art of Laughter." They showed miraculous results in that, patients were laughing and interacting with each other and spoke of their experiences many weeks after the workshop ended. Their spirits were lifted and no one spoke of their disease or depression. It is truly a gift, heaven sent.

Maria Patti does a Sketch Comedy Workshop at Scottsdale Community College. There are eight classes, where people learn to write comedy and perform it in a finale, open to the public. For more information please call Scottsdale Community College 480.423.6321 or contact Maria at Mocomedy7@aol.com.





Join us for our:



2nd Annual Arizona Myeloma Network Charity Golf Tournament

Benefiting Arizona cancer patients

Tournament Chairman and Celebrity Host, Corey La Russo

Thursday, October 5, 2006
Raven Golf Club
at Verrado
12:00 noon Registration
1:00 p.m. Scramble Shotgun Start



Contact: Lyman Smith – 480.296.4486 lyman.smith@cox.net Barbara Kavanagh – 623.388-6837 azmyelomanetwork@cox.net

Prizes: 1st – 3rd Teams, Longest Drive, Hole-in-One, Closest-to-the-Pin Foursome: \$495, Single: \$130 (all with Box-Lunch & Dinner) (Reservations Required) Awards, Raffles, Live & Silent Auctions, & Entertainment

Proceeds will fund continuing AzMN Outreach Events and Educational Programs for Multiple Myeloma patients, their families and caregivers.

MULTIPLE MYELOMA IS A COMPLEX AND OFTEN MISDIAGNOSED BONE MARROW PLASMA CELL CANCER THAT ATTACKS AND DESTROYS THE BONE.

Sign up on our website at www.arizonamyelomanetwork.org

'Please Join Our Golf Volunteer Team, August/September 2006'

A great group and you pick your time and task! Day of event volunteers also needed. Call/email:

Barbara Kavanagh - 623.388.6837

azmyelomanetwork@cox.net

Lyman Smith - 480.296.4486

lyman.smith@cox.net

We are also looking for a wide range of talent; accounting, planning, organizing, grant writing, and special events. You will meet other nice people and make a real contribution to the lives of myeloma patients and their families. You can contact us at the address below for further details.

Articles from our readers are welcome and should focus on information directed towards Multiple Myeloma. They should be informative, and contain non-commercial, non-partisan, non-sectarian points of view. Articles are limited to 175 words and will be published free of charge. Editors reserve the right to edit and shorten text as necessary and to refuse article text or advertising in accordance with AzMN by-laws. Articles are due the first week of each month. Please send inquiries to:

Arizona Myeloma Network 20280 N. 59th Avenue, Ste. 115 #448 Glendale, AZ 85308 AzMyelomaNetwork@cox.net

AzMNewsletters and advertisement details and costs are available by contacting us at the above address.



